Adopted Rejected

## **COMMITTEE REPORT**

YES: 26 NO: 0

## MR. SPEAKER:

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Your Committee on <u>Ways and Means</u>, to which was referred <u>House Bill 1487</u>, has had the same under consideration and begs leave to report the same back to the House with the recommendation that said bill be amended as follows:

Delete the committee report of the Public Health Committee

- adopted February 8, 2001.
  Page 1, line 3, strike "subsection (c)," and insert "subsections (c)
  and (d),".
- 5 Page 1, line 12, delete "significant medical".
- 6 Page 1, line 13, delete "illness, death, or".
- Page 1, between lines 14 and 15, begin a new line block indented
- 8 and insert:
- 9 "(8) Congenital adrenal hyperplasia.
- 10 **(9) Biotinidase deficiency.**
- 11 (10) Disorders detected by tandem mass spectrometry, if the
- state department determines that the technology is available for use by a designated laboratory under section 7 of this
- for use by a designated laboratory under section 7 of this chapter.".

1 Page 2, after line 3, begin a new paragraph and insert: 2 "(d) The examinations under subsection (a)(10) are not required 3 until the state department determines that there are sufficient 4 funds in the newborn screening fund from appropriations from the 5 general assembly and gifts and grants to the fund for the state department to pay for the cost of the tests performed under 6 7 subsection (a)(10). SECTION 2. IC 16-41-17-10 IS AMENDED TO READ AS 8 9 FOLLOWS [EFFECTIVE JULY 1, 2001]: Sec. 10. (a) The state 10 department shall develop the following: 11 (1) A registry for tracking and follow-up of all newborns and 12 individuals for screening. 13 (2) A centralized program that provides follow-up, diagnosis, 14 management, and family counseling and support, including 15 equipment, supplies, formula, and other materials, for all infants 16 and individuals identified as having one (1) of the disorders listed 17 in section 2 of this chapter. 18 (3) A laboratory quality assurance program, including proficiency 19 testing. 20 (4) A statewide network of genetic evaluation and counseling 21 services. 22 (5) A system for using, for epidemiological survey and research 23 purposes, any waste blood specimen generated under this chapter. 24 (b) The program described in subsection (a) shall be funded by 25 collection of a newborn screening fee for each newborn screened by a 26 designated laboratory. 27 (c) The state department shall set the fee and procedures for 28 disbursement under rules adopted under IC 4-22-2. The fee must be 29 based upon the projected cost of the program. The state department 30 may not assess the part of the fee that is attributable to tests that 31 are performed under section 2(a)(10) of this chapter. The proposed 32 fee must be approved by the budget agency before the rule is adopted. 33 (d) The designated laboratory shall assess, collect, and deposit the 34 fees established under subsection (c) in the newborn screening fund 35 established under section 11 of this chapter. 36 (e) The state department shall annually review: 37 (1) the newborn screening fee; and 38 (2) the fee assessed by each designated laboratory for testing

under section 2(a)(1) through 2(a)(9) of this chapter.

(f) Waste blood specimens used for the purpose of implementing the system described under subsection (a)(5) may not include the name or other identifying characteristics that would identify the individual submitting the specimen.

SECTION 3. IC 16-41-17-11 IS AMENDED TO READ AS FOLLOWS [EFFECTIVE JULY 1, 2001]: Sec. 11. (a) The newborn screening fund is established for the purpose of carrying out this chapter. The state department shall administer the fund.

- (b) The expenses of the newborn screening program shall be paid from money in the fund. The expenses of performing the tests under section 2(a)(10) of this chapter shall be paid from money in the fund subject to section 2(d) of this chapter.
- (c) Money in the fund at the end of a state fiscal year does not revert to the state general fund.
- (d) The fund consists of appropriations from the general assembly, fees assessed under this chapter, and gifts and grants to the fund.

SECTION 4. [EFFECTIVE JULY 1, 2001] (a) The state department of health shall develop the following:

- (1) Criteria for a laboratory to qualify as a designated laboratory under IC 16-41-17-7 to test for disorders detectable through the use of tandem mass spectrometry under IC 16-41-17-2(a)(10), as amended by this act, and to test for the disorders listed under IC 16-41-17-2(a)(1) through IC 16-41-17-2(a)(9), as amended by this act.
- (2) A process for designating one (1) or more qualified laboratories to serve as a designated laboratory under IC 16-41-17-7 to test for disorders detectable through the use of tandem mass spectrometry under IC 16-41-17-2(a)(10), as amended by this act, and to test for the disorders listed under IC 16-41-17-2(a)(1) through IC 16-41-17-2(a)(9), as amended by this act.
- (b) Except as provided in subsection (c), after the state department of health has developed the qualifying criteria in subsection (a)(1) and the designating processes in subsection (a)(2), the state department of health may designate one (1) or more qualified laboratories under IC 16-42-17-7 to test for disorders

- detectable through the use of tandem mass spectrometry under IC 16-41-17-2(a)(10), as amended by this act, and to test for the disorders listed under IC 16-41-17-2(a)(1) through IC 16-41-17-2(a)(9), as amended by this act. A designated laboratory may use tandem mass spectrometry to test for those disorders listed under IC 16-41-17-2(a)(1) through IC 16-41-17-2(a)(9), as amended by this act, that are detectable through the use of tandem mass spectrometry.
  - (c) The state department of health may not designate a laboratory to test for disorders detectable through the use of tandem mass spectrometry under IC 16-41-17-2(a)(10), as amended by this act, until funds have been received by the state department of health to pay for the tests under IC 16-41-17-2(a)(10), as amended by this act.
  - (d) The state department of health shall apply for a grant through the federal Public Health Service Act and any other federal grants available to expand or improve programs to provide screening, testing, or other specialty services for newborns or children at risk of disorders detectable through the use of tandem mass spectrometry.
  - (e) This SECTION expires July 1, 2006.".

(Reference is to HB 1487 as introduced, and as amended by the committee report of the Public Health Committee on February 8, 2001.)

and when so amended that said bill do pass.

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Representative Bauer